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'Epileptic', 'epileptic person' or 'person with epilepsy'? Bringing quantitative and qualitative evidence on the views of UK patients and carers to the terminology debate

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ABSTRACT

How to refer to someone with epilepsy is a divisive topic. Arguments for and against different approaches, including traditional adjective labels, disability-first labels, and person-first terms have been presented. The preferences of those with epilepsy and their family and friends have, though, never been determined. This study provides this information for the first time. Via epilepsy interest groups and organizations in the UK and Republic of Ireland, 638 patients and 333 significant others completed an online survey. Three distinct phrases were presented: "They're epileptic" (traditional label), "They're an epileptic person" (disability-first) and "That person has epilepsy" (person-first). Participants identified which they preferred and explained their choices. Patients' median age was 39, with 69% having experienced seizures in the prior 12 months. Significant others were typically parents. Most (86.7%) patients and significant others (93.4%) favored the person-first term. Traditional and disability-first terms were "Disliked"/"Strongly disliked". Regression found it was not possible to reliably distinguish between participants favoring the different terms on the basis of demographics. Qualitative analysis of answers to open-ended questions, however, revealed most favored person-first terminology as by not including the word 'epileptic' and by affirming personhood before disability, it was felt to less likely restrict a listener's expectations or evoke the condition's negative association. It was also considered to suggest the person being referred to might have some mastery over their condition. The findings indicate consensus amongst these key stakeholders others for the use of person-first terminology in English. A truly informed debate on the topic can now begin.

1. Introduction

There is disagreement about how to refer to those with epilepsy [1,2] and the topic can be divisive [3–5]. One reason is that the language we use may shape attitudes, not just reflect them [6–9]. Carefully choosing the words we use when discussing epilepsy might therefore provide a mechanism by which to promote more positive attitudes towards those with epilepsy. Epilepsy remains a highly stigmatizing condition [8,10] and negative attitudes about it can have profound effects. They may delay the seeking of help, treatment adherence, and be associated with poorer patient quality of life [11].

Phrases such as "they're epileptic" and "he's an epileptic" have traditionally been used. Many organizations around the world [12,13], including the US Institute of Medicine [14], now object to "epileptic" being used by itself to describe a person. It is seen as rendering the individual 'invisible' by equating them completely with an attribute that has largely negative connotations [8,14,15]. Use of the term "epileptic" could therefore heighten negative stereotypes towards those with epilepsy. So-called 'person-first language' – such as "person has epilepsy" and "people with epilepsy" – is therefore recommended [13,16–18]. It is considered less negative as personhood is affirmed before disability. Other commentators favor so-called 'disability-first language' such as "epileptic person" instead. One reason for this is that by purposefully separating the individual from their disability, 'person-first language' may belittle the challenges of living with a condition like epilepsy [19].

On the other side of the debate however, are those who disagree with any attempts to dictate what language should be used [5]. Reasons include concerns that the process may be counterproductive in promoting contact between those with and without epilepsy (e.g., because of fear of causing offense and ostracising those who use unfavored terminology).

The arguments proposed by those on the different sides of the debate have been largely grounded in opinion and experience, rather than empirical research. What is currently lacking and could move the debate forward in a constructive way is evidence on the preferences of patients and significant others. To date, these key stakeholder views

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Table 1
Participant characteristics.

	Patients (N = 638)	Family and friends (N = 333)
Age		
Median (IQR)	39 (28–49.25)	46 (39–55)
20–31 years	198 (31.0)	46 (13.8)
32–42 years	168 (26.3)	80 (24.0)
43–51 years	142 (22.3)	98 (29.4)
52–81 years	130 (20.4)	109 (32.7)
Sex (n/%)		
Female	489 (76.6)	298 (89.5)
Male	149 (23.4)	35 (10.5)
Ethnicity (n/%)		
White British	604 (94.7)	319 (95.8)
Other	34 (5.3)	14 (4.2)
Main spoken language		
English	626 (98.1)	327 (98.2)
Other	12 (1.9)	6 (1.8)
Confidence in English if not first language		
"Very well"	5 (41.7)	5 (83.3)
"Well"	7 (58.3)	1 (16.7)
"Not well"	0 (0.0)	0 (0.0)
"Not at all"	0 (0.0)	0 (0.0)
Highest educational attainment (n/%)		
Basic school certificate or lower	169 (26.5)	85 (25.5)
Advanced school certificate or equivalent	142 (22.3)	66 (19.8)
University degree, diploma or higher	327 (51.3)	182 (54.7)
Employment (n/%)		
Employed (full/part-time)/student	389 (61.0)	217 (65.2)
Homemaker/other	172 (27.)	108 (32.4)
Unemployed	77 (12.1)	8 (2.4)
Main epilepsy doctor (n/%)		
Primary care	142 (22.3)	–
Hospital specialist	371 (58.2)	
Equally shared between primary care and specialist	125 (19.6)	
Age at diagnosis		
Median (IQR)	18 (12–27)	–
Years diagnosed		
Median (IQR)	16 (7–28)	–
Antiepileptic medication (n/%)		
None	28 (4.4)	–
Monotherapy	272 (42.6)	
Polytherapy	338 (53.0)	
Seizures (any type) prior 12 months[a] (n/%)		
Yes	441 (69.1)	–
No	197 (30.9)	
Median (IQR)	5.0 (0−10)	
Experience convulsive seizures? (n/%)		
Yes	478 (74.9)	–
No	160 (25.1)	
Nocturnal seizures only? (n/%)		
No	546 (85.6)	–
Yes	92 (14.4)	
Reported cause of epilepsy		
Unknown	429 (67.2)	–
Acquired brain injury	90 (14.1)	
Other	119 (18.7)	
Medical history (beyond epilepsy) (n/%)		
None	356(55.8)	–
Another medical diagnosis	202 (31.7)	
Psychiatric diagnosis	32 (5.0)	
Both medical and psychiatric diagnoses	45 (7.5)	
Stigma score[b]		
Not stigmatized (score 0)	132 (20.7)	–
Mild to moderate (scores 1–6)	385 (60.3)	
High stigma (scores 7–9)	121(19.0)	
Relationship to patient		
Spouse/partner	–	40 (12.0)
Parent		234 (70.3)
Friend		24 (7.2)
Child		11 (3.3)
Other[c]		24 (7.2)

have not been systematically obtained and published [1]. It remains unclear therefore which, if any, of the arguments so far presented within the literature reflect theirs.

To address this, we conducted an exploratory study that surveyed a large sample of persons living with epilepsy and significant others. We asked what their preferences were when referring to those with epilepsy and what their reasoning was. We also tested which, if any, of their characteristics were associated with their preference.

2. Methods

2.1. Participants

Participants were persons with epilepsy and significant others (i.e., family members, informal carers, friends). All were aged ≥18 years. Those with epilepsy were those who self-reported a clinical diagnosis of epilepsy (all syndromes and seizures types permitted). People were excluded if they could not provide informed consent or independently complete questionnaires in English.

2.2. Procedure

Between December 2015 and February 2016, a cross-sectional online survey was conducted. Participants were recruited by advertisements placed in the newsletters and on the websites of epilepsy interest groups and organizations within England, Scotland, Wales, and the Republic of Ireland (acknowledgements). Persons wanting to take part were directed to an online survey page hosted by Qualtrics.

The University of Liverpool's Institute of Psychology Health and Society Research Ethics Committee approved the study (IPHS-1516-SMc-105). Informed consent was obtained from all participants. Meta-data helped identify duplicate responses and these were excluded.

2.3. Measures

2.3.1. Characteristics

Patient and significant other participants reported their demographics and medical history. The information asked for is detailed in Table 1. Of note, both those with epilepsy and significant others were asked to complete Thapar et al.'s [20] scale to provide an estimate of the number of seizures (of any type) that they or the patient they knew had experienced in the previous 12 months. Those with epilepsy also completed Jacoby's 3-item Stigma of Epilepsy Scale [21]. It asked them to what extent, because of their epilepsy, they felt other people (1) are uncomfortable with them, (2) treat them as inferior, and (3) prefer to avoid them. Participants responded to each statement using a 4-point Likert-type scale (0 = not all; 1 = yes, maybe; 2 = yes, possibility; 3 = yes, definitely). Scores range from 0 to 9; 0 indicates the person does not feel stigmatized; 1–6 indicates the person feels mildly to moderately stigmatized; and scores of 7–9 indicate the person feels highly stigmatised.

2.3.2. Preference on how to refer to someone with epilepsy

Participants were presented with the following instructions which were adapted from Kenny's et al.'s [22] examination of language preferences for autism: "People use lots of different words and expressions when talking about epilepsy. Some of these you might like, but others you might dislike. We are now going to ask you some questions to find

Notes: IQR = interquartile range; n = number; SD = standard deviation.
[a] Thapar et al.'s scale which asks "How many attacks have you had in the last 12 months?" The participant can choose from the following ordinal categories: 0, 1, 2, 3, 4, 5, 6, 7, 8, 9, 10 or more.
[b] Jacoby's 3-item Stigma of Epilepsy Scale asks individuals to what extent, because of their epilepsy, they feel other people (1) are uncomfortable with them, (2) treat them as inferior, and (3) prefer to avoid them. Participants respond to each statement using a 4--point Likert-type scale. Scores range from 0 to 9.
[c] Other category includes: siblings, cousins, aunts, and uncles.

out what you think about some words and expressions which people sometimes use." Participants were then presented with three different phrases which represented the traditional approach used to refer to someone ("They're epileptic"), the disability-first term ("They're an epileptic person"), and a person-first approach ("That person has epilepsy").

Participants were asked to identify which *one* term they preferred and also to rate the degree to which they liked each using a five-point Likert-scale (1 = "Strongly dislike", 2 = "Dislike", 3 = "Neither like or dislike", 4 = "Like", 5 = "Strongly like"). They were then asked to explain their choices within free-text boxes.

The questionnaire was piloted to check face validity, understanding, and acceptability.

2.4. Analysis

2.4.1. Quantitative data

Descriptive statistics examined participants' characteristics and their preference for each term. For each term, the proportion of participants who identified it as being their favored term is presented, along with the 95% confidence interval (95% CI). Also presented is the median rating it received on the Likert-scale, along with the interquartile range (IQR). Patients' and significant others' responses were analyzed separately.

With respect to exploring whether any of the participants' characteristics were associated with the one term they favored, there were three terms from which participants could choose. Multi-nominal logistic regression could not however be used due to the small number of participants that ultimately selected the 'disability-first term' (<1%). The inclusion of this category in predictive modelling would have made the resulting model unstable. Therefore it was excluded and, using a reduced sample, binary logistic regression with robust standard errors examined which characteristics were associated with whether a participant favored the traditional or person-first term.

To do this, unadjusted regression was first completed. Where a cell of a categorical independent variable contained fewer than 5 participants, the characteristic was not examined. Any significantly associated ($P < 0.05$) variables were then simultaneously entered into adjusted regression analyses to identify parsimonious predictors. Odds-ratios (OR) along with 95% CIs describe the associations. The c-statistic was calculated for each adjusted model to determine how well label preference could be predicted. It varies from 0.5 (indicating chance prediction) to 1.0 (perfect prediction).

Analyses were completed using STATA 11 (Stata Corporation, College Station, TX, USA).

2.4.2. Qualitative data

Participant explanations were fully-transcribed and an analysis, guided by the principles from inductive thematic analysis, completed [23]. This method is used for identifying, analyzing and reporting patterns (themes) within data without trying to fit it into a pre-existing coding frame, or the researcher's analytic preconceptions.

AR read each transcript line-by-line and generated codes through open coding and thematically categorized these. NVivo 10 was used as a data management tool. Relationships amongst themes were identified through constant comparison of the transcripts, codes, and categories. AN and DS reviewed the codes, their application, and made alternative suggestions until consensus was reached about the interpretation. Patients' and significant others' responses were initially analyzed separately, but later collapsed and analyzed together due to the comparability of themes across the groups.

3. Results

3.1. Participants

One thousand eighty two participants were recruited (695 patients and 387 significant others). Of these, 89.7%, n = 971 (638 patients and 333 significant others) had complete preference data and were included in our analyses. Their full characteristics are shown in Table 1.

There were no statistically significant differences between patients with and without complete data in age, sex or ethnicity (all $P > 0.05$). Significant others with and without missing data also did not differ significantly from one another in age or ethnicity. Males were, though, more likely to have missing data than females (23.9% vs. 12.6%; $P = 0.03$).

The median age of those with epilepsy was 39 (IQR = 28–49.25) and 76.6% were females. Median time since diagnosis was 16 years (IQR = 7–28), most (69.1%) had experienced a seizure (of some type) within the prior 12 months, and 44% reported a co-morbidity. The median age of the significant others was 46 (IQR = 39–55) and most were female (89.5%). Most (70.3%) were a parent to someone with epilepsy. Almost all patients (98.1%) and significant others (97.9%) said English was their first language.

3.2. Quantitative results on language preferences

3.2.1. Preference

The majority of those with epilepsy (86.7%, 95% CI 84.0–89.3) and significant others (93.4%; CI 90.7–96.0) chose the person-first term, "That person has epilepsy", as the one term they favored (Table 2). In keeping with this, the median rating given to it by both patients and significant others on the preference scale was 4, which equates with "Like".

Only 79 (12.4%, 95% CI 9.8–14.9) patients and 20 (6.0%, 95% CI 3.4–8.6) significant others chose the traditional term "They're epileptic" as their favored term, while the disability-first term "They're an epileptic person" was chosen by only 6 (0.9%, 95% CI 0.1–1.7) patients and 2 (0.6%, 95% CI 0.0–1.4) significant others. The median preference ratings given to these last two terms indicated that they were "Disliked"/"Strongly disliked" by participants.

3.2.2. Characteristics associated with term most favored

For patient participants, only their current age and age at diagnosis were significantly associated with the term favored (Table 3). When both variables were entered into an adjusted model, only age at diagnosis remained a significant predictor. It held a small association with preference, with those diagnosed at older ages being less likely to favor the traditional term, "They're epileptic" (adjusted OR = 0.97, 95% CI 0.95–0.98). A c-statistic of 0.58 for the final model indicated poor predictive ability.

For significant others, the only characteristics significantly associated with the term favored in unadjusted analyses were age and how the significant other knew someone with epilepsy. Both remained significant predictors in adjusted analyses. Increased age (adjusted OR = 0.96, 95% CI 0.93–1.00) and being a parent to someone with epilepsy (adjusted OR = 2.61, 95% CI 1.00–6.77) were associated with being less likely to prefer the traditional term. Of the parents, only 3.9% (n = 9) favored this term compared to 11.2% (n = 11) of the participants holding other types of relationship with someone with epilepsy. The c-statistic for this model was 0.69.

3.3. Qualitative comments

Most patients (96%) and significant others (90%) offered comments to explain their preferences and, in some instances, reflected on their experiences of being referred to using the different terms or of using them themselves. Illustrative quotes are provided in Table 4.

3.3.1. Preference for "person has epilepsy"

Participants offered three main reasons for their preferences. The first and most common was that, in contrast to traditional and disability-first language, "person has epilepsy" distinguished the identity of the individual from their condition and so indicated epilepsy could

Table 2
Preferred terms and ratings given to ways to referring to someone with epilepsy.

	Favored term		Rating as to how much they liked it	
Label	Patients n (%)	Significant others n (%)	Patients Median (IQR)	Significant others Median (IQR)
"They're epileptic"	79 (12.4)	20 (6.0)	2.5 (1–3.00)	2 (1–3)
"They're an epileptic person"	6 (0.9)	2 (0.6)	2.0 (1–2.25)	1 (1–2)
"That person has epilepsy"	553 (86.7)	311 (93.4)	4 (3–4)	4 (4–5)

Notes: Higher scores reflect greater preference (1 = "strongly dislike", 2 = "dislike", 3 = "neither like or dislike", 4 = "like", 5 = "strongly like").

be just one of many of their attributes. This was felt to be important so as not to restrict the expectations others had of the person.

Secondly, "person has epilepsy" was considered to suggest that the person being referred to might have some mastery over their condition. In contrast, the traditional term, was seen to imply that the person's epilepsy was all-encompassing, unmanageable, and severe.

Finally, many preferred the phrase because it used "epilepsy" rather than "epileptic". "Epileptic", as a more traditional term, was considered to more likely invoke the negative connotations that epilepsy has had, such as demonic possession, mental illness, and contagious diseases. This, it was said, would likely impede positive contact between those with and without epilepsy.

3.3.2. Preference for "epileptic"

A small proportion of participants held divergent attitudes as they did not favor "person has epilepsy". Two main reasons were presented by these participants.

Firstly, some said they chose the traditional term because unlike the person-first term it did not attempt to 'separate' the individual from their epilepsy. Epilepsy was something these participants said was intrinsic to an individual and should be positively asserted.

The second reason was that by highlighting epilepsy as just one attribute of an individual with epilepsy, "person has epilepsy" actually downplayed the seriousness of the condition. Indeed, several said they would actually favor an alternative term, such as "suffers from epilepsy" to emphasize even further the negative impact epilepsy can have.

4. Discussion

Our study provides, for the first time, detailed, empirical evidence on the preferences of those whose lives are affected by epilepsy about how they want to be referred to. It can be used to help the terminology debate become a truly informed one. While some organizations have previously made recommendations on what language to use, the evidence informing their positions has been largely anecdotal.

4.1. Referring to someone with epilepsy

Our findings are revealing. Persons were asked for their views on a traditional term, a disability-first term, and a person-first term. Participants did not consider these terms as equal. Rather, they disliked the traditional and disability-first terms, but liked the phrase "person has epilepsy". It was the favored term of 9/10 of participants.

Participants' preferences were informed mainly by what effect they felt the terms would have on how the public saw the person being referred to. A number of advantages to the person-first term were identified. Firstly, "person has epilepsy" did not use the word "epileptic". "Epileptic" was considered to evoke the negative connotations associated with the condition in the mind of the listener. It is certainly the case that remnants of some of the "older" ideas about epilepsy still inform some of the public's thinking. For example, in the U.K., over a fifth of the general public agree that those with epilepsy have more personality problems [10]. However, it is not yet known whether the different terms presented to participants do actually evoke these ideas to differing extents.

Participants also favored "person has epilepsy" because it referred to the person first as an individual and then to their epilepsy. In doing so it was seen to focus on a person's humanity and abilities, rather than the pathology. Labelling theorists have argued that social labels, such as "an epileptic", can have a profound impact as they can override other aspects of a person's identity, making it difficult for them to think of themselves or be seen as just "like everybody else" [24]. "Person has epilepsy" appeared to provide a way by which one could try to mitigate against this by reducing epilepsy's salience.

A final reason offered by participants for favoring "person has epilepsy" was that it was perceived as being less likely to imply to listeners that the person's epilepsy was severe and uncontrollable. This concern is discussed more in the 'Implications for future research' section.

4.2. Reasons for not favoring person-first terminology

Only a minority of participants did not prefer the person-first term. Our regression analyses explored what distinguished them from the others. There was a tendency for the significant others to be older and more likely to be a parent to someone with epilepsy, while those with epilepsy tended to be older when they were diagnosed with epilepsy. The ability of this information to predict preference in a reliable way was though, limited. The explanations these participants offered for their choice are more insightful.

One which they offered was that in relegating the prominence of epilepsy, the person-first term trivialized it. While mentioned by only a minority of the sample overall, this raises an important question about what terminology epilepsy organizations would be advised to use in order to promote support for, and awareness of, epilepsy. Inducing empathy for a member of a stigmatized group can improve attitudes towards the group as a whole [25]. The work of epilepsy organizations needs, though, to strike a balance between, as Jacoby [26] puts it, "portraying people with epilepsy as 'no different from you and me' and describing them as different (though not undesirably) and deserving of special treatment" (p. S17–18). It would be appropriate therefore for future work to determine whether the labels differ in the empathy they elicit.

A second concern of participants was that in seeking to separate a person from their diagnosis, person-first language 'colluded' with the notion that epilepsy was to be hidden or ashamed of. Similar concerns about person-first language have been raised by blind [27] and autistic communities [22]. Indeed, Vaughan [19] argued that person-first language precludes pride by violating a tendency for adjectives with positive connotations to precede nouns.

4.3. Implications for future research

Many of our participants believed that the different terms would have an effect on how others thought of or responded to someone with epilepsy. Three studies thus far have tested whether different terms do affect one's views about epilepsy and those with the condition [8,15,28]. They provide little evidence to support our participants' concerns. Noble and Marson [28], for example, examined the labels in English. Over 200 students were randomly assigned to two groups. Their characteristics and epilepsy knowledge were comparable. The

groups completed questionnaires about epilepsy, including the Attitudes and Beliefs about Living with Epilepsy questionnaire [29]. For one group, the questionnaires asked about "people/persons with epilepsy", while the other used "epileptics". No differences were found in participants' responses to any measure. Even in those studies which have reported an effect, these either disappear after corrections for multiple comparisons are made [15] or may be accounted for by methodological limitations to the study [8,28].

So what accounts for the discrepancy between participants' concerns and the results of studies? The labels might simply not have a tangible effect. However, it might be that studies have not measured for the actual effect that our participants are concerned about. Specifically, most studies have tested what effect the labels have on students' beliefs about the risks of epilepsy, how much they would distance themselves from someone with epilepsy, and how stigmatizing the condition is. Our participants though, were concerned with the effect the terms have on the expectations the listener will have of the person being referred to, including how severe and defining they expect that person's epilepsy to be.

Future studies might consider testing for this more nuanced effect since wider social psychology studies suggest that their concerns might be valid [30,31]. Studies by Carnaghi et al. [30] and Raynaert and Gelman [31] involved participants being provided with descriptions of a target using different language forms, such as adjectives (e.g., Paul is

Table 3
Association between participant characteristics and preferred label for those with epilepsy.

Characteristic	Patients (N = 632)			Significant others (N = 331)		
	Preference "They're epileptic" n (%)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	Preference "They're epileptic" n (%)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Age		**0.97 (0.95, 0.99)**	0.98 (0.96, 1.00)		**0.95 (0.92, 0.99)**	**0.96 (0.93, 1.00)**
Sex (n/%)						
Male	16 (10.7)	1.00 Reference	N/A	2 (5.7)	N/A	N/A
Female	63 (13.0)	1.24 (0.69, 2.23)		18 (6.1)		
Highest educational attainment (n/%)						
Basic school certificate or lower	20 (11.9)	1.00 Reference	N/A	8 (9.5)	N/A	N/A
Advanced school certificate or equivalent	22 (15.8)	1.39 (0.72, 2.67)		4 (6.1)		
University degree, diploma or higher	37 (11.7)	0.95 (0.53–1.69)		8 (4.4)		
Employment (n/%)						
Employed (full/ part-time)/student	52 (13.5)	1.00 Reference	N/A	15 (6.9)	N/A	N/A
Homemaker/other	19 (11.0)	0.80 (0.46–1.39)		4 (3.7)		
Unemployed	8 (10.7)	0.77 (0.35–1.68)		1 (12.5)		
Marital status						
Not married	48 (13.0)	1.00 Reference	N/A	6 (5.7)	N/A	N/A
Married	31 (11.7)	0.88 (0.54, 1.43)		14 (6.2)		
Main epilepsy doctor (n/%)						
Primary care	20 (14.2)	1.00 Reference	N/A	N/A	N/A	N/A
Hospital specialist	38 (10.4)	0.69 (0.39, 1.24)				
Equally shared	21 (16.9)	1.23 (0.63, 2.40)				
Age at diagnosis		**0.97 (0.95, 0.98)**	**0.97 (0.95, 0.99)**	N/A	N/A	N/A
Years diagnosed		1.00 (0.98,1.02)	N/A	N/A	N/A	N/A
Antiepileptic medication (n/%)						
None/monotherapy	38 (12.8)	1.00 Reference	N/A	N/A	N/A	N/A
Polytherapy	41 (12.2)	0.94 (0.58, 1.51)				
Seizures (any type) prior 12 months		0.99 (0.94,1.04)	N/A		1.01 (0.90,1.12)	N/A
Experience convulsive seizures? (n/%)						
Yes	62 (13.1)	1.00 Reference	N/A	N/A	N/A	N/A
No	17 (10.8)	0.80 (0.45, 1.41)				
Nocturnal seizures only? (n/%)						
No	71 (13.1)	1.00 Reference	N/A	N/A	N/A	N/A
Yes	8 (8.7)	0.62 (0.29, 1.35)				
Reported cause of epilepsy						
Unknown	49 (11.6)	1.00 Reference	N/A	N/A	N/A	N/A
Acquired brain injury	17 (18.9)	1.78 (0.97–3.26)				
Other	13 (11.0)	0.94 (0.49–1.81)				
Medical history (beyond epilepsy) (n/%)						
None	47 (13.3)	1.00 Reference	N/A	N/A	N/A	N/A
Yes	32 (11.5)	0.84 (0.52, 1.36)				
Perceived stigma						
None (score 0)	19 (14.4)	1.00 Reference	N/A	N/A	N/A	N/A
Mild to moderate (1–6)	42 (11.3)	0.75(0.42, 1.35)				
Severe (7–9)	17 (14.3)	0.99 (0.48, 2.01)				
Do they live with patient? (n/%)						
Yes	N/A	N/A	N/A	13 (5.4)	1.00 Reference	N/A
No				7 (7.8)	1.47 (0.57, 3.83)	
Relationship to patient						
Parent	N/A	N/A	N/A	9 (3.9)	**1.00 Reference**	
Partner/other				11 (11.2)	**3.14 (1.26, 7.85)**	**2.61 (1.00, 6.77)**
Model			**N = 632, X^2 (2) = 12.74, P = 0.002, pseudo R^2 = 0.03 c = 0.58**			**N = 331, X^2 (2) = 9.08 , P = 0.01, pseudo R^2 = 0.07 c = 0.69**

Notes: N/A = not calculable due to the zero cell count. When cell count for an independent variable was <5 no formal test was computed. CI = confidence interval; SD = standard deviation. Entries in bold indicate statistically significant differences ($P < 0.05$).

Table 4
Themes within patient and significant explanations for how to refer to someone with epilepsy and quotes illustrating them.

Theme	Subtheme	Illustrative quotes
Preference for "person has epilepsy"	*Separates individual from condition*	"Epilepsy is a condition you have, but one that doesn't define you as a person. This expression helps separate the two." (Participant ID 375: Patient, female, age 22)
		"I prefer 'person has epilepsy' because the person has more than epilepsy, they have talent, they have a soul, they have a dog … it's just one part of them and this term reflects that." (Participant ID 898: Significant other, female, age 49)
		"There is more to me than my condition. Other terms like "epileptic" and "epileptic person" create a stigma as people are labelled with having a condition and are seen as the same as everyone else that has that same condition even though we all have different personalities and experiences in life which shape who we are."(Participant ID 898: Significant other, female, age 49)
	Implies sense of control and mastery	"I prefer it as it's a more possessive term — especially for a disease that can take over. To say 'he has' or 'I have' gives more of sense of ownership." (Participant ID 221: Patient, female, age 27)
		"I prefer 'person has epilepsy' or 'person with epilepsy' as I haven't had a seizure for several years so I do not like to class myself as being 'epileptic' because it is controlled."(Participant ID 15: Patient, female, age 22)
	Avoids negative historical associations that "epileptic" has	"For me the word 'epileptic' conjures up ideas of possession by devils." (Participant ID 44: Patient, female, age 66)
		"'[*E*]pileptic' is a word so old that it was used in the Bible! It's an historic word which incites a range of discriminatory thoughts, behaviours and invites ridicule and fear in equal measure to the affected person" (Participant ID 44: Patient, female, age 38)
		"The word just sounds and makes people think 'contagious'!" (Participant ID 515: Patient, male, age 36)
		"I do not like the word 'epileptic'. When I say 'I'm epileptic' it scares people, but when I say 'I have epilepsy' it sparks curiosity and I can explain it."(Participant ID 357: Patient, male, age 20)
Preference for "They're epileptic"	*Epilepsy should not be hidden*	"I prefer 'they're epileptic' because it's just the same as the way you say someone is asthmatic, or energetic, it is a characteristic and description of the person as it is part of them as a being." (Participant ID 822: Significant other, female, age 48)
		"I prefer "They're epileptic". Epilepsy is a part of me, no big deal. It's nothing to be ashamed of" (Participant ID 22: Patient, female, age 18)
	Does not belittle significance	"I do not like the 'person has epilepsy'. Epilepsy isn't something we want or that is minor. It is something we have been diagnosed with, and has a hugely traumatic effect on our lives." (Participant ID 617: Patient, male, age 19)
		"I prefer 'they're epileptic' because having epilepsy is horrible. Indeed, I would argue for saying 'suffers from' to emphasise this." (Participant ID 5: Patient, female, age 41)

Notes: There has been minor editing of some to preserve anonymity and to ensure clarity of meaning.

artistic), possessive nouns, and nouns (e.g., Paul is an artist). Nouns induced greater expectations that the target would engage in descriptor-congruent behaviors (e.g., number of paintings they would draw), that they were less likely to engage in incongruent behaviours and the listener interpreted the characteristic being described (e.g., 'artisticness') as being more permanent and stable. Possessive phrases implied a more temporary condition. Labels such as "they're an epileptic" and "they're epileptic" might therefore, as our participants believed, lead listeners to have more negative expectations about the severity and controllability of a person's epilepsy.

4.4. Implications for practice

Traditional phrases are still often used to refer to someone with epilepsy, sometimes interchangeably with person-first language. Krauss et al. [32] reviewed the presentation of epilepsy in the English language print media. Those with epilepsy were called "epileptics" in 45% of stories. Our results indicate reasonable consensus amongst those with epilepsy and their significant others for only using person-first language. The epilepsy community might therefore now be wise to discuss how it might or might not want to encourage such a move and consider wider arguments on the possible advantages and disadvantages of a language change [33].

Some momentum for the change will undoubtedly continue to come from moves away from traditional terms within other spheres, as will high-profile examples of its use [34]. The influential Institute of Medicine [14] has also previously said "epileptic" should not be used in English. They, however, lacked evidence to support the recommendation. It cited only one scientific study [8], and that did not even examine the label in English. Such recommendations could be viewed sceptically. Our study, though, provides evidence from those living with epilepsy themselves which indicates how meaningful and important to them what might seem like subtle word changes are. This evidence could form part of a case for behavior change. Within other realms, more assertive actions have been taken. The American Psychological Association stipulates that person-first language be used in articles published within its journals [35].

4.5. Strengths and limitations

By adopting a person-centered approach and for the first time capturing the views of those with epilepsy and significant others about how they want to be referred to, our study addresses an important limitation in how discussions relating to epilepsy terminology have so far been conducted. Strengths include that recruitment happened across multiple countries within the UK. It also had a large sample, with the views of over 900 persons being captured. This means that the estimates it provides have narrow confidence intervals. The findings may also have international relevance

since the study focused on English phrases. English is the third most widely first-spoken language [36] and the language of science.

The survey approach we adopted may actually be suitable for helping address other issues of contention when it comes to language. We, for example, have used the label "patient" at times in our article to neatly differentiate between participants with epilepsy and significant others. "Patient", some though have argued, implies passivity, lack of personal agency, and lack of value [37]. It may also not be favored when referring to someone when outside of the medical setting. Alternative terms such as "client" and "service user" have been forwarded as preferable. The evidence in favor of their use in epilepsy is though lacking. Interestingly, evidence from the field of mental health shows that those with mental illness actually favored the term "patient", despite calls from many health professionals and patient organizations for use of the alternatives [38,39].

Our study does, though, represent only a first step and there are questions it did not address. Its online nature meant we could not explore participants' views in much detail. We could not, for instance, clarify to what extent participants' preferences might have changed depending on the context in which the person was being referred to and who was doing the referring.

Our patient participants were also slightly younger [40] and more educated [41] than those in the wider epilepsy population. Minority ethnic groups were also underrepresented. This likely occurred because we restricted participation to people who had internet access. While 86% of UK households have internet access [42], cost is a barrier, as is older age.

What effect our recruitment method had also remains to be seen. Adverts for our survey were distributed widely. Not all of those with epilepsy will though receive newsletters from epilepsy organizations or interest groups and the views of those who do might differ from those who do not.

Finally, most (80%) of our participants who had epilepsy reported feeling stigmatized (albeit mildly). Studies using similar recruitment methods found only 52% report stigma [43]. This may be because we used the more sensitive, revised version of the Jacoby Stigma Scale [21]. Nevertheless (and although felt stigma was not associated with language preference in our study), this level of felt stigma and the other unique features of our sample mean future studies should test how well our findings generalize to more representative samples.

5. Conclusions

Our study is the first, to our knowledge, to elicit the views of those with epilepsy and their significant others about how they want to be "referred to". They show consensus amongst these key stakeholders that person-first terminology rather than traditional and disability-first phrases should be used. They felt that this approach was less likely to restrict the expectations that the public have of those with epilepsy and less likely to evoke negative historical connotations.

Conflict of interest

The authors declare that they have no conflict of interest.

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